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Primary care treatment of epilepsy in rural Ethiopia: Causes of default from follow-up

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ABSTRACT

Background: In 1998, we set up nurse-led epilepsy clinics in five rural health centres around Gondar in northern Ethiopia. Despite good treatment outcomes, two years after registration only 40% of patients were still under follow-up.
Aim: The purpose of this study was to examine the causes of default and factors that might improve adherence to follow-up.
Method: The study was carried out at one of the five health centres. Patients who had defaulted from follow-up were identified from the clinic register. Trained enumerators visited the patients' villages and administered a questionnaire to the patients, or relatives if the patient was not available.
Results: 113 patients were traced. 28 (25%) had died and 21 (19%) had moved from the area. Of the remaining 64 patients, seven were accessing treatment from another source and 13 were in remission off treatment. 44 patients were still experiencing seizures and were on no treatment or had reverted to traditional remedies. The main reason given for default, in 44% of the patients, was difficulty in travelling to the health centre. 12% claimed that they preferred traditional remedies and 9% felt that they had not been improved by medical treatment.
Conclusion: Despite decentralisation of care to rural health centres, the most common reason for default was the distance to travel to the health centre. Further decentralisation of care to a community level coupled with improved education may reduce default from follow-up.

Introduction

Epilepsy is an important cause of disability, contributing 7 million disability adjusted life years to the global burden of disease.[1] This burden is particularly evident in less developed countries where epilepsy often remains untreated.

Ethiopia is one of the least developed countries in the world. It has a population of about 70 million, 85% of which lives in rural areas. Epilepsy is the most common cause of neurological disability in Ethiopia. It affects an estimated 5.2 per 1000 of the population,[2] but only 2–13% of people with epilepsy living in rural areas receive medical treatment.[3,4,5] Causes of this 'treatment gap' include inaccessibility of medical services, unavailability of antiepileptic drugs, lack of awareness of medical treatment and cultural factors.

In April 1998, we set up nurse-led epilepsy clinics in five rural health centres around Gondar in northern Ethiopia.[5] A similar programme was also established in four health centres around Jimma in south west Ethiopia.[6] Existing healthcare infrastructure was used and the clinics were integrated with the routine services of the heath centres with few additional resources. More than 5000 patients have now been registered across the health centres in Gondar and Jimma.

In 2001, we reviewed the case records of patients registered at the health centres linked to Gondar.[7] Of those still under follow-up two years after registration, 48% had been seizure free for one year and another 34% had experienced a >90% reduction in seizure frequency. Despite these good treatment outcomes, default from follow-up was a major problem. At two health centres 73% were still attending clinic two years after registration, but overall 60% had defaulted from follow-up by two years. Default has also been a significant problem in Jimma, where 40% of patients were lost from follow-up.[6] Similar default rates have been reported from Zaria and Ibadan in Nigeria.[8,9]

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The reasons for the high default rates are unknown. Most of the patients who defaulted from follow-up did so within two years of registration and thereafter default was rare. Analysis of the health centre records in Gondar suggested that treatment failure and adverse effects were not the major determinants of default and majority of patients were seizure free without significant adverse effects at the point of default. Unreliability of drug supplies and the cost of treatment were suggested as potential causes of default in Ibadan,[9] but this is speculative and there are no reported studies in which patients who have defaulted from follow-up have been traced and the causes of default investigated.

The objective of this study was to trace patients who had defaulted from follow-up to investigate the causes of default and factors that might improve adherence to follow-up.

Methods

We conducted the study in the district surrounding Dabat health centre, one of the five rural health centres with nurse-led epilepsy clinics which are part of the Gondar non-communicable disease project. We chose this health centre because the clinic had a high default rate and because the district includes an area under continual health surveillance by trained enumerators which would facilitate the tracing of patients.

Dabat health centre is 75 km north of Gondar town. It serves a population of approximately 200,000, spread across highland and lowland areas, and is staffed by health officers and nurses. The nurse-led epilepsy clinic was established in April 1998 and 292 patients had been registered and started on treatment with phenobarbital by May 2002.

We performed the study between May and August 2005. We arbitrarily defined default from follow-up as missing three consecutive visits or not attending for $\geq$6 months. We examined the clinic records and identified 165 patients who satisfied the criteria for default. We recorded the patient's personal details, duration of follow-up, and seizure frequency prior to default.

Anticipating the likely difficulties in tracing patients living in remote areas and with constraints on time, we decided to aim for a sample size of 100 patients. We selected patients living in the area under continual health surveillance and in surrounding villages.

We devised a questionnaire, which included information on demographics, seizure control, treatment and reasons for default. Patients were asked to select up to three reasons for default from a list of options and then rank them. The enumerators, already experienced in data collection and in tracing defaulters from a similar study in rheumatic heart disease,[10] were given two days specific training on the questionnaire and the questionnaire was field tested before use.

Tracing of defaulters was attempted through visits by the enumerators to the patients' villages. Mules were used for less accessible areas and village guides were hired to help locate individual households. After obtaining informed consent, the questionnaires were administered to the patient or their legal guardian. If the patient had died, the questionnaire was completed by a member of the family. Surviving defaulters were advised of the date when the next epilepsy clinic would be held at the health centre and were encouraged to attend.

The demographic component of the questionnaire, which included education and measures of wealth, was also administered to 72 consecutive patients under regular follow-up in the epilepsy clinic at Dabat health centre.

Data were analysed using SPSS 10. Descriptive analyses, *t* test and Chi Square test were used.

The study was approved and given ethical clearance by the research and publication office of the University of Gondar.

Table 1
Outcome of patients who defaulted from follow-up

Outcome	Number (%) of patients (n = 113)
Dead	28 (25%)
Moved	21 (19%)
In remission	16 (14%)
Ongoing seizures	48 (42%)

Results

113 patients who had defaulted from follow-up were traced (Table 1). Their median age was 24 years (range 7–75). 6% defaulted after the first clinic attendance. The median duration of follow-up prior to default was 10 months (0–75). 52% had not experienced any seizures for $\geq$2 months before their last attendance.

28 (25%) had died and 21 (19%) had moved from the area. Eleven patients died whilst under follow-up and 17 died after defaulting from follow-up. The majority of the deaths (64%) were related to epilepsy and due to injury sustained during seizures, status epilepticus or sudden unexpected death in epilepsy.

Of the remaining 64 patients, seven were still on treatment (five, although not attending the epilepsy clinic, were obtaining treatment from the health centre and two were obtaining treatment from other sources). 13 were in remission without treatment. 44 patients were still experiencing seizures and were not on treatment or had reverted to using traditional remedies. Of these, 34% were experiencing one or more seizures per week, 34% between one and three seizures per month and 32% less than one seizure per month.

After exclusion of the patients who had died whilst under follow-up, moved from the area or were still obtaining treatment from the health centre, we examined the reasons given for default (n = 76). The most common reason given for default was the distance to travel to the health centre (Table 2) and this was cited as the most important reason by 33%. When additional factors, such as the cost of travel, inability to travel because of the epilepsy and lack of a carer to accompany the patient were also taken into account, difficulty in travelling to the clinic was the most important reason for default in 44%. Preference for traditional treatment was given as the main reason for default by 12%, but it was a contributory factor in 51%. For 9%, the main reason for

Table 2
Reasons given by patients for defaulting from follow-up

	Main reason for default (%) (n = 76)	% reporting as contributory reason for default (n = 76)
Too far to travel	33	64
Unable to travel because of epilepsy	4	26
Cost of travel	4	20
Lack of carer to accompany patient	3	5
Traditional remedies preferred	12	51
No improvement with treatment	9	28
Seizures much improved	8	16
Cost of treatment	3	11
Adverse effects of treatment	4	4
Dissatisfaction with the clinic service	5	7
Seizures returned when treatment finished	1	1
Did not understand the need for follow-up	1	3
Other	13	24

Table 3
Education and measures of wealth in patients who defaulted from follow-up and those still under follow-up

	Defaulters ($n = 76$)	Patients under follow-up ($n = 72$)
Literate	46%	38%
Secondary education	5.3%	14%
Income other than farming	6.6%	8.4%
Iron roof	55%	51%
Mean number of people per room (S.D.)	4.9 (2.0)	5.0 (2.4)
Protected water supply	59%	63%
Sanitation (other than open pit/field)	0.0%	0.0%

default was the lack of response to treatment and this was a contributory factor in 28%. As a group, however, 62% were seizure free at their last clinic attendance compared with only 22% at the time of the study ($p < 0.01$). Only 3% gave the cost of medication as a reason for default and 4% gave the adverse effects of medication.

The mean [S.D.] time for patients who had defaulted from follow-up to travel to the clinic was significantly longer than for patients still under regular follow-up (6.75 (5.12) h compared with 4.93 (5.56) h, $p < 0.05$). 72% relied on walking or mule to travel to the clinic, and only 22% had access to public transport for all or part of their journey. 25% were travelling for $\geq$10 h to reach the clinic and so had to stay overnight before making the return journey.

There were no significant differences in measures of education and wealth between the patients who had defaulted from follow-up and those still under regular follow-up (Table 3).

Discussion

We found a high mortality rate amongst patients who had defaulted from follow-up and greater than expected migration from the area. The majority of surviving patients were no longer on medical treatment and were experiencing frequent seizures. Despite decentralisation of care to rural health centres, the main reason given for default was difficulty travelling to the health centre. Although 9% of the patients who defaulted from follow-up reported lack of improvement with medical treatment as the main reason for default and 12% a preference for traditional remedies, they were much more likely to have been seizure free when they were attending the clinic and it is possible that some of these patients had not appreciated the need for long term treatment.

We did not attempt to trace all those who had defaulted from follow-up at the health centre because tracing patients in rural areas is very time consuming, but 113 from a possible 165 patients were included in the study and we believe that this is likely to be a representative sample. For those patients who had died, the likely cause of death was established by interviewing the patient's family. Confirmation of the cause of death was not possible because there were no medical records or post-mortem data and the findings should be interpreted with caution. The reasons given for default represent the subjective views of the patients and under-reporting of some factors and over-reporting of others cannot be excluded.

To our knowledge, no other studies have specifically investigated the causes of default from follow-up in people with epilepsy in sub-Saharan Africa. In a report on default and non-compliance in Zaria, Nigeria, 18 out of 45 patients (40%) with epilepsy defaulted over a 30-month-period,[8] but the fate of the patients and the reasons for default were not established. The reasons for failure to complete 12 months follow-up were documented in a treatment study in 302 patients in Kenya.[11] Fifty three patients (18%) did not complete follow-up. Of these, 11% died, 25% moved from the study area and 25% withdrew because of adverse effects. 32% did not comply with treatment or refused further treatment, but the reasons for this were not given. The short follow-up period and relatively low rate of withdrawal from treatment may account for the lower proportion of deaths and the higher proportion of withdrawals due to adverse effects compared with our patients.

There are relatively few other data on mortality in people with epilepsy in sub-Saharan Africa. Tekle-Haimanot reported an annual crude death rate of 3.16% in 316 patients with epilepsy living in rural central Ethiopia, twice the mortality rate in people without epilepsy.[4] In a cohort of 128 people with epilepsy in Cameroon, most of whom were not receiving regular treatment, 29% died over a 10-year-period compared with 5% in age-matched controls.[12] This is comparable to the 25% mortality over a period of 7 years observed in our patients, who had defaulted from follow-up. In a follow-up study performed in Tanzania, after 30 years, 67% of 164 patients were known to have died and another 11% were unaccounted for.[13] Mortality was highest when treatment was discontinued or taken irregularly, but was increased even in patients receiving regular treatment. Eleven of the 28 deaths in our patients occurred whilst they were under regular follow-up, but it is not known whether these patients were adhering to treatment when they died. There remains concern that the risks of abrupt discontinuation or irregular treatment with phenobarbital are greater than with other antiepileptic drugs. The majority of the deaths in our patients, and those in the studies from Cameroon and Tanzania, appeared to be seizure related, and measures to reduce default from follow-up and improve adherence to treatment may reduce mortality.

The incidence of epilepsy in less developed countries tends to be higher than in industrialised countries despite similar prevalence rates.[14] This discrepancy is more likely to be explained by a higher mortality amongst patients with epilepsy in less developed countries than a higher rate of spontaneous remission. Nevertheless, it would be expected that a proportion of patients who had defaulted from follow-up and discontinued treatment would remain in remission. A study performed in the UK found that 60% of patients who had been seizure free for two years on treatment remained in remission after drug withdrawal,[15] but there are no equivalent data from sub-Saharan Africa. The majority of our patients had been taking treatment for less than one year before they defaulted from follow-up, but 12% were in remission without treatment.

The World Health Organisation advocates the use of primary health care in less developed countries to improve access to treatment of chronic diseases, such as epilepsy.[16] In Ethiopia, rural health centres, run by nurses and health officers, are the focus of primary health care. Although we have decentralised epilepsy clinics for our patients to rural health centres nearer their homes, the most common reason given for default from follow-up was difficulty in travelling to the health centre. The mean time for a return journey was >10 h and it is not surprising that a proportion of patients was not prepared to make such a long journey regularly. Distance and the cost of travel were not the only problems in getting to the health centre; often patients with epilepsy would not be able to safely undertake a long journey unaccompanied and, unless a family member or friend could be released from domestic or farming duties, they would not be able to attend clinic. Difficulty in travelling to the clinic may also be a factor influencing first attendance; based on a prevalence of 5.2/1000, the total number of patients registered with epilepsy represents less than one third of the expected number of cases within the catchment area of the health centre.

Our findings would suggest that delivery of care closer to the patients' homes would have the greatest potential to reduce default from follow-up. Community health workers and commu-

nity drug distributors, working at a village level, have proved effective in the management of some infectious diseases in sub-Saharan Africa[17] and this could be used as a model for the treatment of epilepsy. There is one report of this approach being used successfully in the treatment of epilepsy in west Uganda.[18]

Patients who had defaulted from follow-up frequently expressed a preference for traditional treatments even though they were much less likely to be seizure free on traditional treatment. It is recognised that patients are sometimes reluctant to admit that they consult traditional healers and it is possible that preference for traditional treatment was under-reported. A study performed in a rural area of central Ethiopia found that 17% of the community believed that epilepsy could be contagious or result from evil spirits.[19] Although the difficulties in travelling to the health centre could have influenced the patients' view of medical treatment, the apparent preference of some patients for traditional treatment may have cultural origins and in part reflect the influence of the patients' families and community. The health centre nurses provide information verbally to patients and carers attending the health centre, but improving education about epilepsy and its treatment represents a further opportunity to reduce default and improve adherence to treatment.

Adverse effects of treatment did not appear to be an important cause of default in our patients. This finding is in keeping with other studies in less developed countries which have shown low rates of withdrawal from phenobarbital due to adverse effects. In the randomised study of 302 adults and children with epilepsy performed in Kenya, only 3.3% of patients on phenobarbital withdrew treatment because of adverse effects (compared with 5.3% on carbamazepine).[11] In a randomised study of 91 children in Bangladesh, there was no significant difference in behavioural adverse effects between phenobarbital and carbamazepine, and there were no withdrawals from phenobarbital during the 12 month follow-up period.[20]

In line with health centre policy, patients who are unable to afford the cost of drugs and have the appropriate papers were given treatment without charge. It is, therefore, not surprising that the cost of drugs was rarely given as a reason for default from follow-up. Even for those patients having to pay for their treatment the cost of phenobarbital is low (approximately 3 USD per year).

Socioeconomic status did not appear to be significant factor influencing default. Interestingly we have previously found that although patients receiving treatment perceive benefits in measures of social, physical, natural and human capital, access to treatment did not influence income (unpublished).

In conclusion, our findings suggest that treatment of epilepsy in rural Ethiopia needs to be decentralised beyond the health centre and what is traditionally viewed as primary care to a community level. Embedding treatment in the community is likely to facilitate the process of educating patients and their communities. Further decentralisation of care coupled with improved education may reduce default from follow-up, improve adherence to treatment and reduce mortality. Our findings are likely to be relevant to the management of epilepsy and other chronic non-communicable diseases in rural areas of other less developed countries with similar primary care infrastructure. As anti-retroviral treatment becomes more widely available in Ethiopia and other countries in sub-Saharan Africa, the findings may also be relevant to the chronic care of patients with HIV infection.

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